

Much More Than A LABEL

A Resource About Personality Disorder By People With Lived Experience

Section **04**

Language and Labels

'Please listen and do not judge me'

This resource has been produced by the Consultation and Advocacy Promotion Service and funded by NHS Lothian

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Much More Than A LABEL

Resource Overview

Why is there a Resource?

The resource has been developed to promote better understanding and support for people with experience of personality disorder diagnosis.

The hope is that the resource can be used in a variety of ways:

- ◆ As a basis for finding out more about personality disorder and what people who have experience of this diagnosis find helpful and unhelpful
- ◆ As a starting point for discussion and reflection amongst staff with an interest in this area
- ◆ As a collaborative tool between service users and workers to discuss their experiences and views and promote a better working relationship

How does the resource work?

This resource has been designed so that people using it can **pick out what is most relevant to them at the time and pick and choose what they want to look at.**

The idea is not to **read the resource from cover to cover** (unless you want to!), but to **pull out and use the section and format that is most useful to you** at the time.

The contents of the resource can be used in a variety of ways, as an **individual, in groups or as a training tool.**

Not everyone will identify with everything in the resource, but the hope is that the topics will **provide some insight into the experiences of service users** who have been given a diagnosis of personality disorder and a **starting point for open discussion and understanding.**

Who is the resource for?

It is for anyone who has an interest in finding out more about personality disorder, but it is especially aimed at staff who work in this area and people who have lived experience of the diagnosis and want to be able to explain their experiences to others.

What is the resource?

It is a collection of information and reflective exercises about the experience of personality disorder diagnosis which has been put together through consultation with people who have personal experience of living with a personality disorder diagnosis.

The resource is written from the point of view of people with lived experience of personality disorder diagnosis and throughout the resource are direct quotes from service users.

The resource has been developed to display information in a variety of ways and to encourage discussion and reflection.

There are sections on:

- ◆ *The Experience of Living with Personality Disorder*
- ◆ *Personality Disorder Diagnosis*
- ◆ *Assumptions and Language*
- ◆ *Support and Treatment*
- ◆ *Attitudes and their Impact*
- ◆ *Living Your Life*
- ◆ *Local and General Resources*

Each section contains:

- ◆ *Section Summary Sheet*
- ◆ *Overviews of Service User Views*
- ◆ *Personal Quotes from Service Users*
- ◆ *Creative Writing or Artwork Contributed by Service Users*
- ◆ *Mind Maps and Word Clouds*
- ◆ *Space to Add Your Own Views and Experiences*
- ◆ *Discussion and Reflection Section*

SECTION 04 : LANGUAGE AND LABELS

Section Outline

Section Summary	1
Assumptions People Make	
The Problem with Assumptions	5
Assumptions We Have Known.....	6
Sticks and Stones May Break My Bones: but words will never hurt me?	
Damned if you do, Damned if you don't	9
Why Might People Come Across This Way?.....	10
Giving an Ultimatum Doesn't Help:	
What To Say and What Not To Say	15
What To Say.....	16
What Not To Say.....	17
Discussion and Reflection Section	
Word Cloud	25
How Does This Relate to Me?	27
Things to Think About	28
Lived Experiences.....	30

Much More Than A LABEL

A Resource About Personality Disorder By People With Lived Experience

Imagine....

How would you feel if people who were supposed to help you made negative assumptions about you before they met you?

How would you cope if all of your reactions to events were labelled manipulative and attention seeking?

How would you manage if people thought it was acceptable to say what ever they want to you when you are in distress?

SECTION 04 : LANGUAGE AND LABELS

Section Summary

A lot of people taking part in the project had found that assumptions were made about them based on their diagnosis. This had a very big and generally negative impact on the people who had experienced this.

Assumption	Problem
Getting upset is a symptom of the condition	It's very dismissive and makes it very difficult to express myself
Looking at the behaviour is more important than listening to someone	Things aren't taken in context and information is missed out, there's no effort to engage
You don't feel what you say you do	It's very invalidating, and doesn't change or improve the situation
Your experience is not valid because it's not the same everyone else's	It's like everything you do is filtered through your diagnosis and people leap to conclusions
That you will be manipulative even if they've never met you	There's a negative atmosphere when you're being treated
Needs aren't what you say they are because of diagnosis	Exacerbates your feelings that you are worthless
You must be exaggerating or attention seeking rather than telling the truth	Makes you question yourself constantly and not seek help even if you need it

Negative Labels

'Damned if you do, damned if you don't'

A number of labels with negative connotations seem to come up time and time again applied to people who have a diagnosis of personality disorder - the most commonly used ones seem to be: manipulative, unco-operative, demanding and attention seeking.

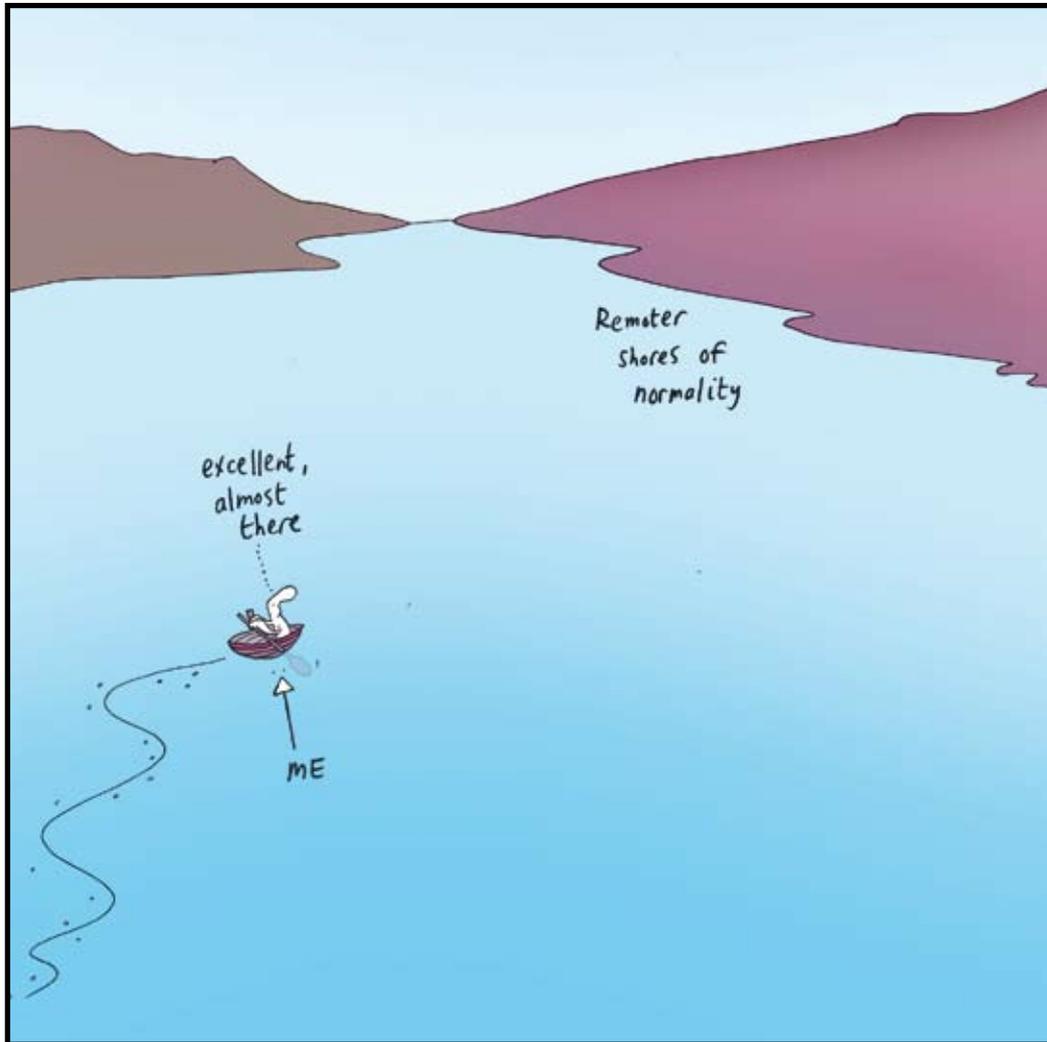
Why Might People Come Across This Way?

Label	My Side of the Story
Demanding	Was given no choices Was talked down to, ignored and ridiculed Own insight and efforts dismissed Had to ask for treatment No compromise on part of service Was given no information or explanations
Unco-operative	Met with a negative attitude Wasn't consulted about anything My experiences were dismissed Everything was my problem and transference Was given inadequate treatment compared to others There was a lack of communication in the service
Manipulative	Was accused of lying because no one checked facts Was assumed to be manipulative People react to my diagnosis and not to me People are not honest with me No one believes me Felt manoeuvred into showing willing
Attention Seeking	Will only be heard if I make a fuss Felt stereotyped, stigmatised and humiliated Was shouted at and things grabbed from me Disorder is blamed for normal reactions Physical illness is assumed to be mental health related People say provocative things to me

What To Say and What Not to Say

Language and how it is used is incredibly important. Helpful comments are not forgotten, but neither are unhelpful ones.

What To Say	What Not To Say
<p>Things which:</p> <ul style="list-style-type: none"> validate explain clearly give hope give a plan help you express yourself acknowledge you as a person give you insight see beyond labels meet you as an equal <p>'That's just a thought, not an action'</p>	<p>Things which:</p> <ul style="list-style-type: none"> dismiss are misinformed are rude are provocative are threatening are over-reactions give you no hope are assumptions are based on a diagnosis not you <p>'It's your personality, change'</p>



SECTION 04 : LANGUAGE AND LABELS

Assumptions People Make

'I'm still the same person'

The Problem with Assumptions

A lot of people who took part in the project had found that other people, especially people giving them support and treatment, made assumptions about them based on their diagnosis. It felt as though they were being viewed through a label and not seen as an individual. People found that being viewed this way and not given a chance to explain things for themselves made them more upset and frustrated.

The following quotes aim to explain what the impact is of having assumptions made about you, as an individual, and also in terms of using support and treatment services.

Assumptions We Have Known...

Assumptions Can Cause Problems...

'I'm still the same person the day I'm diagnosed as I was the day before, but suddenly I'm treated differently'

If I'm treated differently this becomes very confusing and I will probably respond differently as well

'If I get upset or ask a question am I just going to prove the point to you?'

How can I ask questions or express myself if it's always seen as a symptom of my condition - it feels very dismissive

'Some professionals seem to use it to explain my behaviour in preference to listening to me'

E.g. you're suicidal because your therapist is away (no, I've felt like this for weeks, you're just hearing about it because my therapist is away and I have to find someone else to talk to)

'I am not a problem, but a person'

When you feel people are responding to you as a label or a problem first and not as a person it's extremely upsetting and frustrating. Just because you might have problems with your emotions doesn't mean you can't tell if people have a problem with you

'There's a difference between saying look at this objectively and actually there's another way of looking at this and saying no you don't feel that.'

Denying feelings is very invalidating and doesn't change or improve the situation in any way. It's important to work with someone where they are not where you think they should be

'I was being judged on the basis of well she's got this in her notes, when it was real for me'

It can feel like what you say and do is filtered through your diagnosis, and rather than being taken at face value, assumptions are made about you before you are even able to explain what's happening. Your experience is your experience no matter how much someone else doesn't agree with it

'I feel it is them saying I have no intelligence or mind of my own - only BPD'

If your actions and feelings are being interpreted through a diagnosis it makes you wonder if people even see you as a person or just as a label. It can be like losing your identity

'Some people have automatically assumed that I'm going to be manipulative, even when they don't know me or my case'

Everyone is an individual and a diagnosis does not give a blueprint for how every person with that label will act

'I feel like I am stereotyped and my needs not seen as important because of my diagnosis'

Feeling that you are being treated differently and seen as unimportant because of your diagnosis only exacerbates your feelings that you are worthless

'I have met many professionals who are quite patronising when they learn I have Borderline. Believing I'm only playing up for attention when I'm really needing help'

Being dismissed when you are actually asking for help in a potentially serious situation is very upsetting, frustrating and invalidating. You're unlikely to ask for help in advance the next time

'It feels like if you say something you're exaggerating it or it's not true, it's being manipulative or whatever, but no this is what it's really feeling like just now...'

The assumptions other people make about you can leave you questioning your own motives and reality with no one to ask about it. The level of confusion and distress this brings is hard to even describe

I think they aren't able to get right in there and understand what it actually means and what the emotions are...My experience is that they see it as you're just like this revolving door type, really expensive, time consuming, frustrating patient and here we go again, instead of trying to understand what it's like to be inside our heads and to feel those things



SECTION 04 : LANGUAGE AND LABELS

Sticks and Stones May Break My Bones - but words will never hurt me?

Damned if you do, Damned if you don't

A number of labels seem to come up time and time again applied to people with a diagnosis of personality disorder.

People are often told that they are wasting time, they are not ill and that they are being manipulative, unco-operative, demanding or attention seeking.

A lot of people felt that the experiences they had and the responses they got from services and professionals had forced them to respond in a way they would not normally do.

Some of the responses people got from services could also be categorised as manipulative, unco-operative, demanding or attention seeking.

It can sometimes feel that whatever you do it will be interpreted in a negative light.

In addition to this the language that is used to describe you can have an enormous impact.

Why Might People Come Across This Way?

'Demanding'

My Side of the Story:

- ◆ Asking questions meant I had a problem with authority
- ◆ There was no recognition of my efforts - only blame for what went wrong
- ◆ I was informed about what I needed and told to go to it - I felt like I had no choice
- ◆ I had to ask for treatment
- ◆ I was accused of being uppity
- ◆ I was ridiculed
- ◆ There was a lack of compromise
- ◆ I was talked down to and ignored
- ◆ My own insight was dismissed
- ◆ I was given no explanations
- ◆ I was treated like a burden

'Unco-operative'

My Side of the Story:

- ◆ I was not engaged with
- ◆ I was met with a negative attitude and preconceptions
- ◆ I was taken off medication with no consultation
- ◆ I was not consulted or told about my care plan
- ◆ There was a reluctance to refer me on
- ◆ My experiences were not being validated
- ◆ They seemed to want a quick fix diagnosis and it was inflexible
- ◆ Everything was my transference
- ◆ She was too busy to see me
- ◆ There was no response to my requests for help
- ◆ There was a lack of communication - and I fell through the gaps
- ◆ I was not told about appointments
- ◆ I was given different or inadequate treatment compared to other people
- ◆ I was stonewalled or dismissed



'Manipulative'

My Side of the Story:

- ◆ I was accused of lying, because no one checked the information or facts
- ◆ There are very strict rules on the contact I'm allowed with services
- ◆ I was refused access to my notes
- ◆ I was assumed to be manipulative
- ◆ I'm confused by the complexity of the system
- ◆ People's reactions are to my diagnosis first
- ◆ I've felt manoeuvred into showing willing as I was worried about being turned away
- ◆ Being patronised
- ◆ Being judged
- ◆ People haven't been honest with me
- ◆ I'm afraid to complain
- ◆ I'm not believed

'Attention Seeking'

My Side of the Story:

- ◆ I'll only be heard if I make a fuss
- ◆ I had things grabbed from me instead of talking to me
- ◆ Feeling stereotyped
- ◆ Feeling stigmatised
- ◆ Being humiliated
- ◆ Being shouted at
- ◆ The disorder is blamed for normal reactions
- ◆ Being fobbed off
- ◆ Physical illness assumed to be mental health
- ◆ I've been treated like a second class citizen
- ◆ Having provocative statements thrown at you
- ◆ I don't want to upset anyone



Never apologise for showing feeling when you do you apologise for the truth.

Benjamin Disraeli

SECTION 04 : LANGUAGE AND LABELS

Giving an Ultimatum Doesn't Help

What To Say and What Not to Say

This section is included because although most people taking part in the project had received some very helpful and advice and support from a variety of people, there was a strong feeling that often people didn't think about what they said or how large and long-lasting an effect a throwaway or insensitive comment might have.

Again language and how it is used is incredibly important and something that needs to be thought about very carefully.

What To Say

The comments in this section are not intended to be a definitive guide, but to prompt consideration about why these comments were helpful.

Comments that Have Helped

Psychiatrist:

This is one person's view at one moment in time

Psychotherapist:

That's just a thought, not an action

Psychiatrist:

Why don't you go and read up on this symptom and then we'll discuss it

Doctor:

The things that have happened to you have changed you

Psychiatrist:

This is your diagnosis and this is what we're going to do

Support Workers:

Yeah, you're angry so shout it out, tell us about it

GP:

If you need to contact me during the week just give me a call

GP:

I don't know but I'll try and find out

Psychiatrist:

It's not your diagnosis that's important, it's what issues are you having and what can we do about them

What Not To Say

The following are all things that have been said by professionals to people who took part in the project.

The quotes and the reasons why they were felt to be unhelpful have been included. This section is intended to get people to think about why these comments were unhelpful and what might be a more constructive or helpful thing to say. It is also to highlight the impact of a comment that the speaker might not have given a second thought to. It also illustrates the importance of listening to someone when they say they find a specific phrase or comment unhelpful. Some of these comments had been said repeatedly.

And Why Not to Say It

Psychiatrist:

You don't want to bother doing that (response to overdoses)

Because: it doesn't help with the actual problem, it's dismissive

Social Worker:

It's down to you to stop self harming

Because: it's not really a choice when you don't know it's a choice

Emergency Assessment Team Psychiatrist:

What an odd young man

Because: it was a psychiatric assessment service!

Psychiatrist:

You're a tosser, you're pathetic

Because: you're a human being

Psychiatrist:

You have an untreatable illness

Because: it's not true and it leaves you in a hopeless situation

A&E Nurse:

Why don't you kill yourself properly?

Because: you're a human being

Psychiatrist:

You'll come across some very sick people and they'll cause you to deteriorate (response to idea of peer support group)

Because: it denies your own self-determination and awareness (and peer support)

Psychiatric Nurse:

If you cut while you're here (in hospital) - you're out

Because: it doesn't help address the problem, it's a threat

Psychotherapist:

Well that's not very intelligent (response to self harm)

Because: I know it's not, but I still can't stop, if intelligence was all it took...

Psychiatric Emergency Team (and many, many others):

Go and have a hot bath/shower

Because: it doesn't change anything and if it doesn't work I won't have the energy to call and tell you and you'll think it's fine

CPN:

Well I don't find it negative; I find it quite interesting (response to Personality Disorder diagnosis)

Because: am I a specimen in the zoo?!

GP:

We don't have anyone else like you; it's mainly professional people who come to this surgery

Because: I feel I can never go back there

Psychiatrist:

There are iller people than you

Because: it doesn't change your situation; it's not a competition

CPN:

Your life is like a soap opera; I'm happy to come and see you and find out what happens next

Because: it belittles my problems

Surgeon:

Right you have to stop doing this. Either stop doing it or go to another hospital, we do not have the time to keep treating you here

Because: it's intimidating and threatening when you're very vulnerable

CPN:

I don't want to hear that (response to suicidal feelings)

Because: it doesn't help you address the problem; it's invalidating

SHO:

Well I think that's highly inappropriate (response to 'Where did you graduate?')

Because: it's a bit of an over-reaction to small talk - and makes you wonder is it perhaps a reaction to your diagnosis rather than you?

Psychiatrist:

You can control it

Because: it's way too simplistic and doesn't give you any idea of how to control things; it feels very dismissive

Psychiatrist:

Most women diagnosed with a personality disorder don't reach forty

Because: it's not exactly positive or helpful - I expect you to die!

Psychotherapist:

You've destroyed our relationship by making assumptions (response after asking 'What do you think of me?')

Because: felt manipulated and backed into a corner

Psychiatrist:

People with your diagnosis usually end up killing themselves

Because: basically I expect you to die!

Psychiatrist:

Why do you want to see me? Unless you're dying, do not call me again

Because: you're obviously not at all important, you have to justify yourself

GP:

If you keep doing things like that then you are going to have this diagnosis

Because: it suggests you're doing it because you feel like it

Psychiatrist:

I really don't know what to do with you

Because: you think oh no what do I do now?

Psychiatrist:

We're not admitting you - there's nothing wrong with you

Because: it's incredibly dismissive

CPN:

I think you need anxiety management - I've spoken to someone - you start next week (never mentioned before)

Because: decisions are taken out of your hands, your own insight is dismissed

SHO:

There's nothing we can do for you medically, it's your personality; you have to change

Because: it's a dead end, basically be someone else

SHO:

When you cried you made me feel like I was bullying you

Because: it's an assumption, you're the mad one, I felt bad it must be your fault

Psychotherapist:

If you have abandonment issues we won't start therapy

Because: it made me feel there's no hope at all

crying - a poem

i have always felt that i mustn't cry
particularly when it really
isn't on
to make a show
of myself.

Where did i get that idea from?
Is it the ancestors speaking?
After all i never met Nanny,
well not face-to-face
I know i felt threatened
when told to
"stop crying or i'll smack you".

Did those words
really get spoken
or is that what
i heard inside
I remember getting smacked on
the leg when upset at
the dinner table;
the force of Daddy's hand
banging my leg off
the table leg which
did not give as my leg did
but held its own and bruised my own
which made me cry all the harder
and i heard you tell him that i was hurt
(now physically as well as emotionally).

How absurd to tell a child
that they will be punished if
they don't stop crying
if they don't
stop being frightened
if they can't
act like a ___year-old.

I have cried myself to sleep
more often than i've had stories
read to help me fall asleep

I have wept over books and films
and news and lovers and friends
I have howled in rage,
whimpered in fear,
made myself sick with distress
and despair.

Oh yes, i cry all the time
well, most days anyway
and it hurts
it feels like
a surge of
electricity
coursing through
my veins
and i can't hold
it in
and i can't
switch
it
off
i have to
ride it out
until
it has
all
been
emptied
until
i am
empty.

Clients cry
and i run out of tissues
and they wipe
their eyes
and blow
their noses
on hand-towels
rough
and
scratchy

not
soft
and
comforting
and somehow i feel
honoured that they
can cry with me
i feel that we have had
a breakthrough.

I am their confessor at times
- an old man tells me he had a big row
with his wife and there were tears
and he wonders if he's depressed
and he wonders if she's taking care
of herself as well as she is of him...

Tears
- dissolving (rage, fear, surface of my skin),
scalding (my cheeks, another's shoulder)
salty (if only i had advance warning of crying
i would take out my contact lenses first)
messy (snottiness, puffy eyes, dishevelled)
but utterly human and unavoidable
at least for you and me...

leti hawthorn

SECTION 04 : LANGUAGE AND LABELS

Discussion and Reflection Section

Word Cloud

The following page contains a Word Cloud which gives a summary of some of the experiences that have been described in this section.

This has been included to give an alternative view of people's experiences and a visual representation of the descriptions in this section.

The Word Cloud was created by typing a jumble of words related to a specific topic. The words which are repeated most often come out in a larger font to represent their relative importance.

The Word Cloud tries to represent a cross section of the experiences of the people who took part in the project and all of them may not relate directly to everyone.

There is information in the introduction section about how to create your own Word Clouds.

labelled
stonewalled
accusations
upsetting
invalidating
humiliated
patronising
stigmatised
negative
interpretations
fobbed
off
insight
stereotypes
questioning
motives
preconceptions
dismissive
not
consulted
not
believed
inflexible
judged
ridiculed
unimportant
treated differently
assumptions
too
busy
frustrating
worthless

How Does This Relate to Me?

This page has been included for you to add your own views and feelings on this section, and anything else you want.

Things to Think About

What is your reaction to the sections you have just looked at?

How do you think service users who have had these experiences might feel afterwards?

What impact do you think these types of experiences might have on someone seeking help?

Why do you think these situations arise and what could you do to try and prevent them from happening?

Artwork in this Section:

Have a look at the artwork/poetry in this section.

What do you think the creator was trying to express in the picture/poem?

How do you think the creator might have felt at the time?

Some contributors have written an explanation about their artwork.

P4 Remoter Shores of Normality

Is this where I am, or the shore I'm striving to reach? Who's defining 'normal'?

P8 Tumbling

This demonstrates the fragility of how I see calmness and normality, how easy it is to fall down the spiral of anger and further into complete emptiness and despair.

P11 Light at the End of the Tunnel

After accepting the diagnosis, I was ready and motivated to move on/change. But any route I tried hit a dead end, and my MH team told me there was no plan and no hope - I was now BPD and just a problem.

P13 Doing Badly

A collage.

P21 crying

A poem.

Lived Experience

Have a look at the following questions and discuss them. How do you think experiences like this would affect service users respond to services?

Have you ever had an experience where someone has made assumptions about you?

Have you ever had someone talk about you in a way you felt didn't really reflect what had happened?

Have you ever been in a situation where you have been dismissed or ridiculed?

How did you feel and respond in these situations?

Did you feel your response was reasonable? Why or why not?

How do you think your communication style might change if you were very upset, angry or confused?

How would you like people to respond to you if you were upset, angry or confused? What do you think would influence how you respond to them?

Notes

A series of horizontal dotted lines for writing notes.

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